



IN THE HIGH COURT OF JUSTICE

No.FD14P00912

FAMILY DIVISION

**2014 EWHC 4861 (Fam)**

Royal Courts of Justice

Friday, 8<sup>th</sup> August 2014

Before:

MRS. JUSTICE KING

**(In Private)**

Re AA

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*Transcribed by **BEVERLEY F. NUNNERY & CO.**  
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**J U D G M E N T**

(As approved by the Judge)

MRS. JUSTICE KING:

Introduction:

The application with which this judgment is concerned was heard on 14 August 2014, due to the extreme urgency of the matter, an extempore judgment was given at the conclusion of submissions. The following is the transcribed and amended version of that short judgment now published in accordance with the *Practice Guidance of 16 January 2014: Publication of Judgments*.

- 1 This is an application made on behalf of Great Ormond Street Hospital for Children NHS Trust (GOSH), for a declaration that it is lawful and in little girl, AA's, best interests for artificial hydration to be withdrawn. AA was born on 31<sup>st</sup> July 2002, and has therefore just turned 12 years of age.
- 2 AA was born with a serious brain malformation. This has meant that, throughout her short life, she has suffered from multiple, untreatable, medical and developmental difficulties. AA functions on the cognitive level of a baby of about six weeks of age and an optimistic assessment of her mobility would place her at the level of a six-month-old baby.
- 3 In summary AA has hydrocephalus and severe epilepsy, she is, and always has been tube-fed, and is visually impaired to the extent that she can only see shapes and some light. AA is significantly developmentally delayed and has no useful mobility.
- 4 Throughout her life, AA has been cared for with complete devotion and commitment by her mother, with the assistance of her maternal aunt and maternal grandmother. No one can begin to imagine the challenges faced by this family in caring for AA, a measure of not only the love and devotion but also the competence shown by the family in caring for this little girl is revealed not only by the fulsome praise of the family found within the medical reports, but also by the fact that, AA was sent home in the early months of her life in the expectation that her death would soon follow, it being anticipated that she had either weeks or months to live. No one involved in her care could possibly have anticipated that she would survive for over a decade. It is recognised by both her family and the medical professionals that despite having defied the odds for so long, AA is now reaching the end of her life.
- 5 Whilst AA has, as one would have expected, spent periods of time in hospital, she has largely been cared for at home. It is evident from the papers that she has, in her own small closed world, had some modest quality of life afforded to her by virtue of the love and devotion of her family.

- 6 Unhappily in the last 18 months or so, AA has become increasingly intolerant of her feeds; this intolerance manifests itself in screaming episodes. The screaming is brought on not as a consequence of AA being resistant to being fed, or because she does not wish to be fed, but simply because she is in pain. The doctors and nurses caring for AA have tried various strategies to cope with this new and deeply distressing phase of AA's inevitable deterioration. For many months, the hospital managed the problem by stopping AA's feeds for a period of time and then gradually, gradually reinstating them; this procedure is no longer proving effective as a means of ameliorating AA's pain and distress.
- 7 The matter has now come before me as an urgent application; AA's situation has further deteriorated to the extent that she now screams in pain for hours on end and recently, for a 24-hour period, she was utterly inconsolable. All the strategies, all the knowledge, all the medical science available to the experts in both palliative care and in pharmacological medicine at GOSH have been unable to control her pain. Morphine and ketamine are not fully effective, despite being given extremely high doses. Other drugs have been tried to no avail and the team have tried to administer drugs subcutaneous, but that too, can only be tolerated in the short term.
- 8 AA will inevitably become increasingly intolerant to the medication she is being currently given in an attempt to damp down her pain; it is common ground that the management of her pain is only going to become increasingly difficult, and less effective.
- 9 Concerns for AA became so great that, on 30<sup>th</sup> July 2014, the Ethics Committee of the hospital met in order to try and reach a decision as to what treatment plan was now in AA's best interests. I have had the benefit of witness statements from Dr. Prabhakar, Consultant Paediatric Neurologist, who is the lead consultant involved in AA's care and from Dr. Dilini Rajapakse, who is the consultant in paediatric palliative medicine at GOSH. I have also read a second opinion in the form of an independent medical report from Dr. Anderson from the Marsden, which report was prepared at the request of the Ethics Committee.
- 10 I have also read a witness statement from Mrs. Strickman; her statement has been invaluable to the court in considering where AA's best interests lie. Mrs Strickman is the ward manager of the ward where AA is currently nursed and she sees AA on a virtually daily basis, Mrs Strickman knew AA as a baby and has been constantly involved in her nursing since she was readmitted to her ward on 24<sup>th</sup> July. Her statement gives the reader real insight into just what AA is going through as her life comes to an end; hers is no easy passing, but pain and anguish every step of the way.

- 11 A decision was reached at the Ethics Committee that, because of AA's intolerable and unmanageable pain, the time had come to stop giving AA nutrition; this decision was reached with the agreement of the mother and all the experts.
- 12 Following the Ethics Committee meeting, the mother was persuaded, I suspect somewhat against her better judgment, to allow AA to continue to be hydrated after nutrition was withdrawn. AA's condition however, has continue to deteriorate, and she is in constant unmanageable pain; the medical view as well as the mother's view is that the time has come when even keeping AA hydrated is no longer in her best interests.
- 13 Part of the dilemma faced by AA's mother, the Ethics Committee and the doctors caring for her is that whilst AA is terminally ill, she is not "actively dying", in that her heart continues to beat, she receives oxygen but is breathing, otherwise unassisted, she is therefore in no immediate danger of dying. That is however a simplistic way of looking at the situation: AA's condition is irreversible; she is dying, it may not be today, it may not be tomorrow but it will be soon. The consequences of a refusal of the declaration sought is that AA will continue to be in appalling pain for so long as it takes for her either to get a chest infection and die from pneumonia or, for there to be a breakdown of her vital organs.
- 14 Over the last 24 hours or so her breathing has become more difficult and her secretions are now thick and mucous. It may well be, I am told by the consultant in palliative care, that she is now succumbing to a chest infection, which infection will lead rapidly to her death.
- 15 I have a letter from AA's mother, dated Wednesday, 6<sup>th</sup> August. It says as follows:

*"For the last two weeks, since arriving at Koala Ward, AA has deteriorated significantly. The overwhelming pain and suffering has taken my, once, happy, smiling daughter away from me, and all I see now is a beautiful child who is in extreme agony, day in and day out; whose complexion once resembled that of an English rose, is now grey and sallow. Every touch and every movement from AA is met with ear-deafening screams and cries, so I cannot even comfort my daughter any more and this, alone, is heart-breaking. But the fact that I have to watch my angelic child endure such an horrific existence for a possible ten-plus weeks or, even, months is too much to bear. My daughter is no longer my daughter; she is now merely just a shell. The light from her eyes is now gone and is replaced with fear and longing to be at peace.*

*Today, I am appealing to you for AA, as I truly believe that she has endured enough and for me to say that literally breaks my heart, but I have to say it. As, always, I have lived my life for the best interests of AA and, now, removing fluids is what is best for my child to stop the pain and suffering and for her to be finally at peace, as I do not want the rest of her time here fraught with tears and sadness.*

*I want beautiful memories and, if this is made to last much longer, I know there will not be, and my daughter deserves the most dignified, peaceful passing possible, where I do not have to worry about the medical nursing side of things. We can spend our remaining days together, just as we have always done, side by side as mother and daughter, holding her hand, knowing I have done everything I possibly can for her now to be at peace."*

### The Law

- 16 The court must ascertain what is in AA's best interests when considering whether to make a declaration that it is lawful for life-sustaining treatment to be withheld.
- 17 I take the law from the judgment of Peter Jackson J in *Re KH (Medical Treatment: Advanced Care Plan)* [2013] IFLR 1471 based as it was on the judgment of Holman J in *An NHS Trust v MB (a child represented by CAFCASS as guardian ad litem)* [2006] EWHC 507 (Fam) [2006] 2 FLR 319, para 16. It is not necessary to rehearse the well established law set out in these judgments.
- 18 Peter Jackson J sets out [para 11] an excerpt from the publication *Withholding or Restraining Life Sustaining Treatment: A Framework for Practice (2<sup>nd</sup> Edition) May 2004*. [Since the hearing of this application this has been superseded by a third edition in March 2015]. The framework sets out at 3.1.3. *Circumstances of Withholding or Withdrawal of Treatment*: This identifies three different situations in which consideration may be given to the withholding or withdrawal of treatment they are:
- The "no chance" situation.
  - The "no purpose" situation.
  - The "unbearable" situation.

AA's situation undoubtedly falls within "no chance" situation:

"The "No Chance" Situation is a state of affairs where:

*Treatments delay death but neither improves life's quality nor potential. Needlessly prolonging treatment in these circumstances is futile and burdensome and not in the best interests of the patient; hence there is no legal obligation for a doctor to provide it. Indeed, if this is done knowingly (futile treatment) it may constitute an assault or European Convention on Human Rights. Consider for example a child with progressive metastatic malignant disease whose life would not benefit from chemotherapy or other forms of treatment aimed at cure."*

Whilst not determinative, consideration of the above criteria is of assistance in determining where AA's best interests lie. Against the backdrop of the totality of the evidence available to the court today it is hard to see how the continuation of treatment is other than "burdensome" to AA, existing as she does in a state of unremitting pain.

### Discussion

19. AA's case has been considered with the upmost care by the Ethics Committee and the court has, as set out above, the benefit of AA's mother's views as to her best interests. AA's case is one of those cases, not unknown but fortunately relatively uncommon, where the court is faced with making a decision as to whether a declaration is in the best interests of a child in circumstances where death is not imminent in terms of minutes or hours, although is inevitable.
20. Extending AA's life to some modest extent will, in my judgment, not only be of no overall benefit to her but will, according to the unchallenged medical opinion, subject her to the continuation of the unremitting and unmanageable pain she is suffering.
21. In my judgment the conclusion reached by the Ethics Committee and the courageous decision of her mother that it is no longer in AA's best interests to be hydrated, is undoubtedly correct and in her best interests. As a consequence of the care and dedication of her mother, AA has had a length and quality of life which could never have been envisaged when she was born. I accept without hesitation that to seek to prolong her life, now is contrary to her best interests and accordingly grant the declaration sought.